Alive and Clicking
How patients are changing healthcare
Paul Hodgkin FRCGP
Patient Opinion – Founder & Chair
Everyone has a public voice

Dear Dr, I'm the wrong side of 35, please don't say 'Good Girl' to me while fitting an IUS however well-meant. You're a woman & I'm a woman!

10 Jan via Twitter for iPhone ★ Favorite Retweet Reply
"How my mother is left for two hours needing the toilet and sitting on a chair for 5 hours, waiting for her bed to be made."

My mother is left needing the toilet for hours and they are not able to clean or change her sheet. This is not a one off as it has happened for hours because her bed is not made and no one assists her.

Every day I have to take her clothes home to be washed because she is incontinent and her urine, from being left on the bed pan for hours. Where does her care come from within our country. The staff I have met do not seem to be that enthusiastic and their commitment is very upsetting. How people can be left in this state and not be given the care and attention they deserve.

Something needs to be done to make the right changes so these type of scenarios aren’t allowed to go on. Shame on the NHS.

Activity:

- Staff members have read this story
  - 1 at Care Quality Commission
  - 1 at Royal College of Nursing
  - 4 at University Hospitals of Leicester
  - NHS Trust
  - 1 at Liz Kendall’s Office, MP for Leicester West
It's easy to find people like me

Cure the NHS
Campaigning for better NHS care

Welcome

Latest: 400 dead in NHS Killing Field

Our group was created by people who have lost relatives or were victims of poor care and support within mid Staffordshire Foundation trust Hospitals at Stafford and Cannock. Poor management and lack of suitably trained and dedicated staff are to blame and we are committed to change the management and ethos of the trust so we may all feel safe and secure if admitted to the Hospitals.

Our Aims

- Improve the services and care within the Mid Staffs Foundation trust.
- Provide support and advice to other victims.

This website provides information for who need help and advice about how to deal with the hospital and how to help a relative in there. It also provides information on our campaigns to raise awareness of the problems. If you cannot find the information your require or would like to offer your support then please do not hesitate to contact us.
Its easy to find out what is ‘normal’

My vaginal lips are purplish they hav been like that for a while *note i was rapped at age 5* and i was wondering why they are like that and if there is anything i could do to fix them... please help

Asked on 3 Feb 2012 05:06 by Nicole
replies - can you help?

Answer this now
Report as Offensive

Hello, I am nearly 14 and I am not sexually active. Recently I have started to get a yellowy coloured discharge it smells and it is worrying me abit, I am to scared to see a doctor as I would feel to uncomfortable but I wondered is there anything else I can do about it? also I am worried about the look of my vagina my labia hangs lower on one side than it does the other, is this normal?
"Empathy flowing both ways can only help lead to better health outcomes."

Posted by OPP (as the patient), 10 months ago

Going back into hospital doesn't get easier just because you are a regular. If anything it gets even tougher because you know what is in store. I have just returned home after a ten day stretch and further surgery.

I take great pride in the fact that my care is very much a partnership between patient and healthcare professional. Empathy has been talked about as a key component in the partnership. In fact I have read many articles about the best doctors are those who show empathy to their patients. After much exploration though I struggled to find articles that talk about patients who can empathise with their doctors. We can debate why this is the case for ages but for me perhaps one reason is that we often choose to take for granted the work that our HCPs do in helping us. Whilst we all want collaboration and partnership maybe that doesn't always extend to a real understanding of what the medics go through.

I think that I am just as guilty as others in this department. That was until this particular in-patient stay.

The day before I went in to hospital my surgeon and I had a very open telephone call about the surgery. Nothing unusual there except I do remember thinking that he being even more cautious than normal and very specific about each individual point and potential consequence. I knew that post-transplant surgery is inevitably more complex than pre-transplant so again I sort of shrugged it off. Arriving in hospital something didn't feel quite right. Not about my health but about the atmosphere on the ward and the way he spoke to me. Again I was told that he would do absolutely
11 Health

The company was founded by Michael Seres, a long term patient who turned innovator.

Michael was diagnosed with the incurable bowel condition Crohn’s Disease aged 12. After over 20 operations and intestinal failure he became the 11th person to undergo a small bowel transplant in the UK at The Churchill Hospital, Oxford, England. His own experience as an ostomy patient led him to designing the initial Ostom-i prototype whilst recovering from transplant. A published author and professional speaker Michael is a Stanford Medicine X e-patient scholar and develops patient engagement strategies for hospitals, primary care trusts and patient groups. He has a background in consumer product licensing and merchandising having worked with major brands such as Fifa, UEFA, The X Factor and The Apprentice.
# Multiple Sclerosis

We're all in this for good.

By sharing your stories and data, you will:

- Help each other today
- Help raise awareness

What do patients take to treat Multiple Sclerosis and its symptoms?

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Perceived effectiveness</th>
<th>Overall rating of side effects</th>
<th># of Evaluations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glelamer acetate (Copaxone)</td>
<td></td>
<td></td>
<td>1644</td>
</tr>
<tr>
<td>Interferon beta-1a IM Injection (Avonex Pen, Avonex Prefilled Syringe, Avonex)</td>
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<td>904</td>
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<tr>
<td>Interferon beta-1a SubQ injection (Rebif RebiAdose, Rebif)</td>
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<td></td>
<td>842</td>
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<tr>
<td>Natalizumab (Antetegren, Tyvyri)</td>
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<td>679</td>
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<tr>
<td>Interferon beta-1b SubQ Injection (Urbena, Extavia, Betaseron, Betaseron)</td>
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<tr>
<td>Fatigue</td>
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<td>Brain fog</td>
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<tr>
<td>Excruciating pains</td>
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<tr>
<td>Loss of sensation</td>
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<tr>
<td>Stiffness/Stiffness</td>
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<tr>
<td>Dalfampridine (4-AP extended release) (Ampyra, Fempyra)</td>
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<td>218</td>
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<tr>
<td>Pain</td>
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<tr>
<td>Depressed</td>
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<tr>
<td>Mood swings</td>
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<tr>
<td>Bladder problems</td>
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<td></td>
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<tr>
<td>Bowel problems</td>
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</tbody>
</table>

384 MS patients report no overall side effects for Natalizumab (57%)

Talk to people with MS

Multiple Sclerosis Forum

- Multiple Sclerosis
- Greater New York Chapter
- Blog
- Podcast
A **community of practice** exists around the clinical service

A **community of solidarity exists** around the patient
The **community of practice** is under pressure as never before

The **community of solidarity** is getting ever more organised

Web forums, PatientsLikeMe HealthKit
Making the community of solidarity more effective

What is Howz?

An app that helps you (the Howzer) stay connected with your elderly or frail relative (the Howzee), wherever you are.

Communicate with your whole family in one click
Patient’s Howz circle
A LAENNEC PATTERN STETHOSCOPE.

The stethoscope was introduced to Guy's by Hodgkin in a lecture to the Physical Society in October 1822.
Power without love is reckless and abusive

Love without power is sentimental and anaemic.
Business as usual?
Thank You

If you would like to discuss these issues more then do please contact me at paul.hodgkin@patientopinion.org.uk

Or via Twitter: @paulhodgkin

For more about Patient Opinion see www.patientopinion.org.uk or email info@patientopinion.org.uk

Latest blog:
eHealthInsider – ‘Technology is the architect of our intimacies’
You can have any treatment you want, as long as it's Nice.
TOO BIG TO KNOW

RETHINKING KNOWLEDGE Now That the FACTS AREN’T
the FACTS, EXPERTS Are EVERYWHERE, and
the SMARTEST PERSON in the
ROOM Is the ROOM

David Weinberger
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Total Number of MOOCs – June 2013 to June 2014

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So this is where we are now. The world is driven by pathways and protocols. Change is achieved by changing the rules.

‘Rules and targets drive quality’
This ‘regime of discipline’ aims to make clinical behaviour more systematic. It costs around £1 billion per year.

‘The task of the clinician is to inscribe the defined care on the patient’s flesh’
Society of Acute Medicine

Title ‘Alive and Clicking’ How patients are changing healthcare
Access to information and social media is changing healthcare:
• Power is shifting from organisations to citizens
• The nature of evidence is changing
• Patients are beginning to generate and own their own data and records
These trends are reshaping healthcare

The world is cracking open – science and socially
• Follow the money:
  • in last decade NHS spent £10bn on IT via CfH.
  • UK citizens spent £100 bn
• Everyone has a voice
• Nature of evidence is changing
Title Alive and Clicking: how patients/ ‘the people’ are changing medicine
Networked individualism – distributed capital, information and voice

Three asymmetries – information, power and vulnerability and the historical trajectory of these over last 100 years – low – higher – down

Changes in evidence – filter forward not filter out – for every fact there is an equal and opposite fact. The most intelligent person in the room is the room
Evidence is just not evenly distributed

Regime of discipline breaking down

Changes in information – access, non esoteric yes; but also data from bio sensors; from people like me; MOODOCs

Changes in power – Occupy the NHS

Changes in vulnerability remain – the existential fear of death. Gravity

So looking out 10 years what will medicine look like?

All the technical progress of course but also:

Relational
The world is cracking open and as it does so its changing medicine – genomic,s proteomics, micro-biomics, imaging, therapeutics
But it is also changing patients relationship to medicine – just as profound but less obvious
Different ways to listen to patients – stethoscope –
Also practiced acute medicine, understood institutional politics,
Micael’s story – he has a voice. He has power – falling barriers to entry, showing who has read the story
- Bt also making somethongn hidden open – like so much – patients compassion for us
- Also changing nature of medicine – too big to know; any treatment you like but NICE
- PLM – brain fog – video

Medicine built round doctors knew more, doctors were more powerful, patients were vulnerable
These are cracking open.
My great, ... uncle Thomas. ??
Power and love
The standard human chicken